

**OPTN/UNOS Patient Affairs Committee
Report to the Board of Directors
November 12-13, 2014
St. Louis, Missouri**

**Kristie Lemmon MBA, Chair
John Fallgren RN, Vice Chair**

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This report reflects the work of the OPTN/UNOS Patient Affairs Committee during the period of June, 2014 to September, 2014.

Action Items

None

Committee Projects

1. Clarify Policy Language and Process for Individual Wait Time Transfer

Public Comment: Spring 2015 (estimated)

Board Consideration: June 2015 (estimated)

Current language in Policy 3.6.C Waiting Time Transfer fails to outline actions and specific responsibilities in the waiting time transfer process. There are exceptions to the standard transfer of waiting time, such as:

- transfers involving multiple registrations
- transfers involving a gap in time between registrations
- transfers involving an overlap of time with two or more registrations

Current policy language does not address how waiting time will be transferred in these specific instances.

This project is to intended to

- clarify the process for waiting time transfer
- clarify responsibilities for patients, transplant programs and the OPTN Contractor within the waiting time transfer process
- define the responses to the situations outlined above within policy language. This will result in policy that is applied more consistently and takes steps to ensure that a

The Subcommittee addressing this project will take the suggested policy language to the full committee for review during the October 20, 2014, Committee meeting.

2. Pediatric to Adult Care Transition Project

Public Comment: N/A

Board Approval: N/A

Within the transplantation literature, long term outcomes for transplant recipients between the ages of 11 and 19 show higher rates of acute graft failure, graft loss and mortality. The highest rates of graft loss occur between the ages of 11 and 34. UNOS Research Staff

identified a correlation between the incidence of graft loss and the transition from pediatric to adult care. Transition is defined as an active process that addresses the medical, psychosocial and educational/vocational needs of adolescents as they prepare to move from pediatric-focused to adult-centered care.

The Committee consulted with the Pediatric Committee and the UNOS Communications Department to consider appropriate methods for encouraging early and effective planning for transition from pediatric to adult care among parents. The pediatric page on www.transplantliving.org was a logical starting place for disseminating patient/focused resources.

The Committee has worked with UNOS Communications Department Staff to develop appropriate language, encouraging early preparation for transition to adult care. The Committee also plans to incorporate pediatric transition into the planned update of *What Every Patient Needs to Know*. The target completion date for this phase of the Pediatric Transition Project is June 2015.

3. Develop Policy to Address Safety Concerns Related to Large Volume Waitlist Transfers

Public Comment: January 2015 (Estimated)
Board Approval: June 2015 (Estimated)

Available literature, data and practical clinical experience indicate that adolescents have a higher rate of graft loss than any other group of transplant recipients. Long term outcomes include higher rates of acute rejection, graft loss and mortality for recipients between the ages of 11 and 19. A review of available graft survival 5 years post-transplant shows an average of 25-30% graft loss occurs between the ages of 11 and 34. After a review of the available data, the Pediatric and Patient Affairs Committees determined that one method for addressing this issue is to develop patient resources that encourage early and thoughtful preparation for transition to adult care.

Available data indicates that these patients lost their initial graft in their late teens or early 20's, during the time when transition to adult care would be expected to occur.

The Committee developed language for a patient focused *Frequently Asked Questions* document. This document will be included as part of an online toolkit for transplant programs. For additional information on this project please see the **Operations and Safety Committee's Report to the Board** and the Minutes from the September 23, 2014 Operations and Safety Committee meeting.

4. The Patients Guide to Referral to Kidney Transplantation

Public Comment: N/A
Board Approval: N/A

The Committee continues to be involved with the Minority Affairs Committee in the Patient's Guide to Referral to Kidney Transplantation project. For more information see the **Minority Affairs Committee's Report to the Board** and the Minutes from the July 8, 2014 Minority Affairs Committee's meeting.

Committee Projects Pending Implementation

None

Implemented Committee Projects

None

Review of Public Comment Proposals

Committee leadership reviewed the list of proposals released for comment on March 14, 2014. It was determined that the full Committee would review 10 of the 17 proposals put forth. The remaining seven proposals were made available to the Committee for individual review and comment. The Committee reviewed three proposals prior to the June 2014 Board Report. The other proposals slated for full committee review were subsequently reviewed by the Committee.

The Committee received presentations on the following proposals from the leadership of each Committee. Committee comments and votes are summarized below.

5. Proposal to Modify Existing or Establish New Requirements for the Psychosocial and Medical Evaluation of all Living Donors (Living Donor Committee)

After a lengthy discussion, the Committee asked that the following points be considered with the proposal: 1) Transplant programs should be encouraged to develop their own organ specific consents, which reflect risk of death and center-specific outcomes. 2) Informed consents should quantify the increased risk of death with both center specific and national statistics, 3) Informed consents should state the increased risk of living liver donation as compared to living kidney donation.

Committee Vote (For – 16, Against – 0, Abstain – 0)

6. Proposal to Align OPTN Policies with the 2013 PHS Guideline for Reducing Transmission of Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV) Through Solid Organ Transplantation. (Ad Hoc Disease Transmission Advisory Committee (DTAC))

The Committee received the presentation on this proposal. Committee members verbalized their support of the proposal. The Committee considered the specific questions raised in the proposal, but did not offer feedback.

Committee Vote: (Support – 16, Abstain – 0, Against – 0)

7. Proposal to Require the Collection of Serum Lipase for Pancreas Donors (Pancreas Transplantation Committee)

The Committee received the presentation on serum lipase and voted with minimal discussion.

Committee Vote: (Support – 15, Abstain – 1, Against – 0)

8. Proposal for Adolescent Classification Exception for Pediatric Lung Candidates (Thoracic Organ Transplantation Committee)

The Committee received the presentation and supported the proposal.

Committee Vote: (Support – 15, Abstain – 1, Against – 0)

9. Proposal to Notify Patients Having an Extended Inactive Status (Transplant Coordinators Committee)

The Committee received the presentation on this proposal. The Committee overwhelmingly agreed that notification of inactive status is important for transplant candidates. There was also discussion regarding the time requirements for notification. Some members of the Committee felt notification should be required earlier in the process.

Committee Vote (For – 11, Abstain – 2, Against – 1)

10. Proposal to Cap the HCC Exception Score at 34 (Liver Committee)

The Committee received the presentation on this proposal. The Committee considered the specific questions raised in the proposal, but did not offer feedback.

Committee Vote: (For – 11, Abstain – 0, Against – 0)

11. Proposal to Delay the HCC Exception Score Assignment (Liver Committee)

The Committee received the presentation. See the results below.

Committee Vote: (For – 11, Abstain – 1, Against – 0)

12. Proposal for Modify ABO Determination, Reporting and Verification Requirements (Operations and Safety Committee)

The Committee received the presentation.

Committee Vote: (For – 11, Abstain – 0, Against – 0)

13. Proposal to Modify ABO Subtyping References for Consistency (Operations and Safety)

The Committee received the presentation.

Committee Vote: (Support – 11, Abstain – 0, Against – 0)

Other Committee Work

14. OPTN Website Redesign Review

UNOS Communications Department Staff provided periodic updates on the redesign of the OPTN website. The Committee felt the updated design allowed information to be easily accessed from the home page. The new design also makes public comment review more accessible to the average user. The Committee found the layout and overall appearance of the new design to be engaging and easy to interact with. The Committee participated in a survey designed by the UNOS Communications Department to test usability of the website and found very positive results.

Meeting Summaries

The committee held meetings on the following dates:

- May 1, 2014
- June 5, 2014
- July 10, 2014
- August 7, 2014

Meetings summaries for this Committee are available on the OPTN website at:
<http://optn.transplant.hrsa.gov/converge/members/committeesDetail.asp?ID=14>